

What Communities

Value

About Health
and Health Care



Community Voices
HEALTHCARE FOR THE UNDERSERVED



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www.communityvoices.org

As states and the nation continue to deliberate about health care, the well-being of 70 million underserved Americans hangs in the balance.

Through its Community Voices Initiative, the W.K. Kellogg Foundation is working to strengthen local health safety nets and to give the underserved a voice in the national dialogue on health reform.

When we talk about “the underserved,” we mean people who do not have access to appropriate, affordable, and timely health care. The reasons are often financial, but can be further complicated by geographic, language, and cultural barriers.

Being underserved is a community experience as well as an individual one. Individual health is shaped by a multitude of physical, social, and political variables. We believe that working within a community context offers the best way to understand the complex dynamics of health and develop effective strategies for improving it.

The W.K. Kellogg Foundation is funding 13 communities across the country to serve as learning laboratories on health care for the underserved. They range from dense urban neighborhoods to remote rural towns, and cover a broad racial and cultural spectrum. The communities have engaged more than 5,000 people in public forums, focus groups and surveys on health. Across the diverse groups, a common message is emerging.

What Communities Value About Health and Health Care

*Here, in their own words,
is what people in
communities value most
about health and health care.*

- **Trust & respect**
- **Care for the “whole person”**
- **Care when and where
people need it**
- **Affordable coverage for
everyone**
- **Healthy communities**

Trust & Respect



- **31 million U.S. residents (or 11% of the population) are foreign-born.**

(U.S. Census Bureau, 2000)

- **70% of the public supports customizing health services to the needs of different cultural groups.**

(Community Voices National Survey for the W.K. Kellogg Foundation, 1999)

“Doctor, talk to me and listen to what I am saying,” is one woman’s message. “It may not be the ailment I’m coming in with today. It may be something that happened last week, and I’m not making the connection.”

Across communities and cultures, people place high value on their relationships with their health providers. They say good relationships are founded on mutual respect and trust. Such relationships require time, commitment, communication, and understanding.

“A patient may need time to talk,” explains one nurse. “There are a lot of emotions that go into a person’s illness. When people don’t know what’s going to happen, they become very anxious. For us to be able to ease some of that anxiety is a key part of what we do. It helps to increase their ability to get better.”

Unfortunately, time is at a premium in today’s health care system. Health providers “have got to see more patients, see them quicker, see them more efficiently, and do it for less,” one health care administrator says.

“What I value - and I hear this a lot in our community - is respect for our culture when services are provided.”

Continuity is another key to relationship-building. “We don’t get the same doctor each time,” one father says. “So each doctor doesn’t know the condition of my kids. He has to go on hearsay of what this doctor wrote or that doctor wrote.”

Language is central to good relationships. “If you don’t have an interpreter, it is as if you are blind,” says a Vietnamese woman, who gave birth at a hospital where there was no one to translate for her. “You just sit there, and people do things to you, and you feel very afraid.” Few communities where multiple languages are spoken have enough medical interpreters due to a lack of trained translators and because their services are not covered by most health plans.

“What I value — and this is what I hear a lot in our community — is respect for our culture when services are provided,” says a Hispanic man who runs a social service agency. Most people say that they do not choose their health care providers based on their race or culture, that other factors such as competence and sensitivity are most important. But they do want providers who understand and honor their cultural beliefs and traditions and recognize their impact on health.



- **One in five Americans is affected by mental health or substance abuse disorders in a given year; only a third of those affected receive any kind of treatment.**

(Marguerite Ro and Lucy Shum, "Forgotten Policy: An Examination of Mental Health in the United States," W.K. Kellogg Foundation, 2001)

- **88% of the public believes that access to mental health services should be guaranteed to everyone.**

(Community Voices National Survey for the W.K. Kellogg Foundation, 1999)

Care for the "Whole person"



"All these things have to be aligned when you talk about health care - the mental, the physical, the emotional, the spiritual," says one man. "They're all spokes in the same wheel."

People want a health care system that treats the entire person. They want the different types of care they receive to be coordinated with each other. They want to take charge and be active partners in their own health.

People view prescription drugs as an integral, yet often ignored, aspect of health care. "The current system is intolerable," says one woman. "My husband can't treat many of his patients because they can't afford the medications."

People also see vision and dental services as basic, not "extras." "My first trip to the dentist was after I had my first child," a woman remembers. "We have to make sure that that doesn't happen to our young people today."

"When we talk about cardiac health, no one would say 'let's make that an option,'" says a hospital administrator. "Oral health is a more hidden issue, but it's part of a holistic way of being healthy."

“Even if I needed counseling, my insurance company would only allow a certain number of times I could be seen.”

People with long-term conditions want services that are not subject to arbitrary and inappropriate limits. “There are a lot of mental health problems that aren’t being addressed,” one man says. “I was in a program, but they ran out of money. So now I don’t get to see a psychiatrist or a therapist.”

“Even if I needed counseling, my insurance company would only allow a certain number of times I could be seen,” says a social worker who works with homeless people. “When you’re chronically mentally ill, you need it all the time. You need supportive services in order to stay out of hospitals, out of jails. The jails have become a place where so many acutely mentally ill people are, and that’s so tragic.”

“My son needs orthopedic services,” says the mother of a child who has cerebral palsy. “But his insurance does not cover it. I found a program that would help pay for a wheelchair. He was measured for it three years ago. It just came in, and now it is too small for him.”



Care When & Where People Need It

- **Uninsured people are half as likely as people with insurance to get preventive health care.**

(The News Hour with Jim Lehrer/ Kaiser Family Foundation National Survey of the Uninsured, 2000)

- **69% of the public support moving financial resources out of specialized medicine and into preventive and primary care.**

(Community Voices National Survey for the W.K. Kellogg Foundation, 1999)

“I lived with asthma, probably for years, and suffered because I didn’t know where to go and was petrified of accumulating more bills,” a woman recalls. “I lost time from work and probably didn’t get enough time with my children because I was ill.”

People in communities say that we should focus our energy and resources on providing services when and where people need them. That means identifying and treating problems in a timely fashion at locations that are accessible to people.

“The resources are there,” one man insists. “But right now, we’re still focused not on a health care system, but a sick care system. There just is not enough emphasis on prevention.”

Education is key. “I lost a good friend to undiagnosed diabetes,” a minister says. “I was working with him as usual on Friday and, by Monday, he was in the hospital. He had no idea he had diabetes. That made me start a series of health seminars at our church so people would know what to look for to keep themselves healthy.”

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Location is another factor in getting timely care. Many communities find that schools, workplaces, and senior centers are ideal places to provide health screening and primary care. “We bring a mobile health van here three or four times a year,” says one employer. “They do a lot of preventive care, like mammograms and blood pressure checks. You’d be surprised at how much we pick up from those screenings, and then can refer people to health providers in the area for treatment.”

Waiting is a big deterrent to many people seeking care. “I was really sick and had to sit at the clinic for three hours,” an elderly woman says. “I finally told them to reschedule me because I was too sick to stay, and it was time for my medication, which I have to take with food, so I had to go home.”

People are concerned about the racial inequalities that exist in health and health care. “I was just reading an article in the *New England Journal of Medicine* about kidney transplants,” one doctor says. “African Americans, even when they’re at the same stage of disease as Caucasians, don’t have access to kidney transplants at the same rate that Caucasians do. In terms of access to health care, there are huge disparities between people of color and the community at large.”



Affordable Coverage for Everyone

- **Nearly three-quarters of uninsured Americans live in families where at least one person works full-time.**

(Kaiser Commission on Medicaid and the Uninsured, 2000)

- **79% of the public is in agreement that access to health care should be guaranteed.**

(Community Voices National Survey for the W.K. Kellogg Foundation, 1999)

“I felt very uncomfortable going to a hospital and expecting health care when I had nothing,” a woman recalls. “You lose your dignity. You’re begging to be healthy, begging for what everyone should be entitled to – health.”

Most people agree that everyone in America should have access to affordable health care. This belief is shared by both rich and poor, by the insured and uninsured. They view the problem as too big for any one entity to solve alone. Most support a pluralistic approach to health care financing that involves individuals, employers, and government.

Most people favor employment-based health insurance, but also acknowledge the shortcomings of this approach. “I grew up in a working class family back when you could get a job with decent wages and benefits,” one man says. “Now, when new jobs come in, they’re low-wage without benefits. In terms of quality of life, there are light years of difference.”

Rising health insurance costs are a problem for all employers and often prevent small employers from offering coverage at all. “I just had an employee who was in the hospital,” said a small businesswoman. “I felt so bad. If I was able to afford to offer insurance, maybe she would have gone to the doctor before it got to that point.”

“It boils down to this, either you buy food or you buy drugs.”

Government-sponsored health plans help, but do not go far enough. “It boils down to this,” says an elderly woman covered by Medicare. “Either you buy food or you buy drugs. I also need major dental work that I just can’t afford.”

Immigrants face particular challenges in getting health coverage. Restrictive eligibility requirements can result in some family members being insured while others are not. “I do not feel right,” says one father. “What good is it if I’m the only one to get health benefits?”

Some people are reluctant to apply for government health plans. “There’s quite a stigma just walking through our doors to apply for any type of assistance,” one social worker says. Outreach to people who are eligible for government-sponsored health plans is essential to overcome the formidable barriers to enrollment and care. “The system is set up for people who have cars, jobs and money, who have education, who know how to speak the same language,” says another social worker. “We take so much for granted.”



Healthy Communities

- **More than one in ten Americans (32.3 million people) lives in poverty. Poverty rates for Blacks and Hispanics are three times higher than for Whites.**

(U.S. Census Bureau, Current Population Survey, 2000)

- **People with annual incomes under \$7,500 are almost twice as likely to die prematurely as those making more than \$32,500.**

(Davey-Smith, G., J.D. Neaton, and J. Stamler, 1996)

“We like to be around our families,” one woman says of her Hispanic culture. “So whether it’s health care, housing, or transportation, these issues matter to us in the same way because they all affect our families.”

Although they may express it in different ways, people across cultures view individual well-being as connected to the well-being of their families and communities. They care about the social, economic, and environmental factors that impact their personal and collective health.

“People don’t look at health in this community like we health professionals look at it,” says a local public health director. “They wouldn’t measure it the way a doctor measures blood pressure and cholesterol. They’ll want to know about crime, about housing, about jobs, and about their own ability to make decisions about their lives. That’s what people see as making this a healthy community or not.”

People say that poverty undermines communities and erodes health. “The problem I see with health care is the lack of jobs in the area,” says one man. “The average person around here is probably making about six to eight dollars an hour and not getting benefits. If you take eight dollars an hour times 40 hours a week, that’s not much money to pay for health care and everything else.”

“You have to have health, public safety, employment, and economic development all working together. . .”

People are concerned about the fates of families leaving welfare. “The reports say they’re doing good by coming off welfare,” one woman says. “But what do they mean by ‘doing good?’ They don’t have transportation; they have child care issues. There’s just so much affecting these families.”

Immigrant communities are hit hard by low-paying and sometimes risky jobs, lack of benefits, and substandard housing. “Landlords tend to be very neglectful of their properties in my neighborhood,” one woman says. “There are a lot of immigrants living here, and many of them are undocumented. The landlords feel they can take advantage of them and don’t fix what needs to be fixed.”

People feel that improving health requires a broad-based effort. “We’re building relationships beyond the medical profession,” says the leader of a local health coalition. “You have to have health, public safety, employment, and economic development all working together concurrently in building up the community.”



Toward a Health Agenda That Includes Everyone

The 13 local Community Voices Initiatives are engaging thousands of people in examining health issues and setting directions for dealing with them. They are forging coalitions and networks among health providers and other community organizations to tackle tough problems. They are bringing the voices and experiences of underserved communities to inform health policymakers and practitioners. They offer several important findings about improving health care in the United States:

There is broad-based support for significant changes in health care.

Across the country, people from all walks of life are deeply concerned about health and health care for themselves and others. They feel our current policies have failed to contain costs or assure access and that these failings are jeopardizing the health of ever-growing numbers of people. While people bring different perspectives to the issue, they agree on certain fundamental principles. Health care, they say, should be universal, affordable, timely, and holistic.

Relationships are essential components of health and health care.

While there have been tremendous advances in medical technology, people say the equally important human aspect of health care has suffered. They want to rebuild relationships on all levels, from patient care to community mobilization to public policy-making. Regardless of their race, culture, or income, people want to be active partners in efforts to improve the health of their families and communities.

Societal biases that affect health must be understood and overcome.

However well-intentioned they may be, health policies and practices are affected by the same prejudices that permeate the society. These in turn lead to unacceptable disparities in health care for the poor and for people of color, undermining our basic American value of “fairness.” In order to create a compassionate, quality system of care, we must recognize and change the actions we take as a society that exclude people.

No one entity can create meaningful change alone.

Many communities are doing an admirable job of expanding health care access using the piecemeal array of existing programs. But most people believe that the challenges of providing care to everyone surpasses the capacities of most communities and even states. People say that they do not want “government-run health care,” but they do believe that federal, state, and local governments are critical partners in working with the private sector to assure access and quality.

Community Voices Local Initiatives

California Rural Indian Health Board

Camillus House, Miami

Community Voices, El Paso

Community Voices, Oakland

Community Voices Collaborative, District of Columbia

Denver Health

FirstHealth of the Carolinas

Ingham County, Michigan, Health Department

Northern Manhattan Community Voices

University of New Mexico Health Sciences Center

Vision for Health Consortium of Baltimore

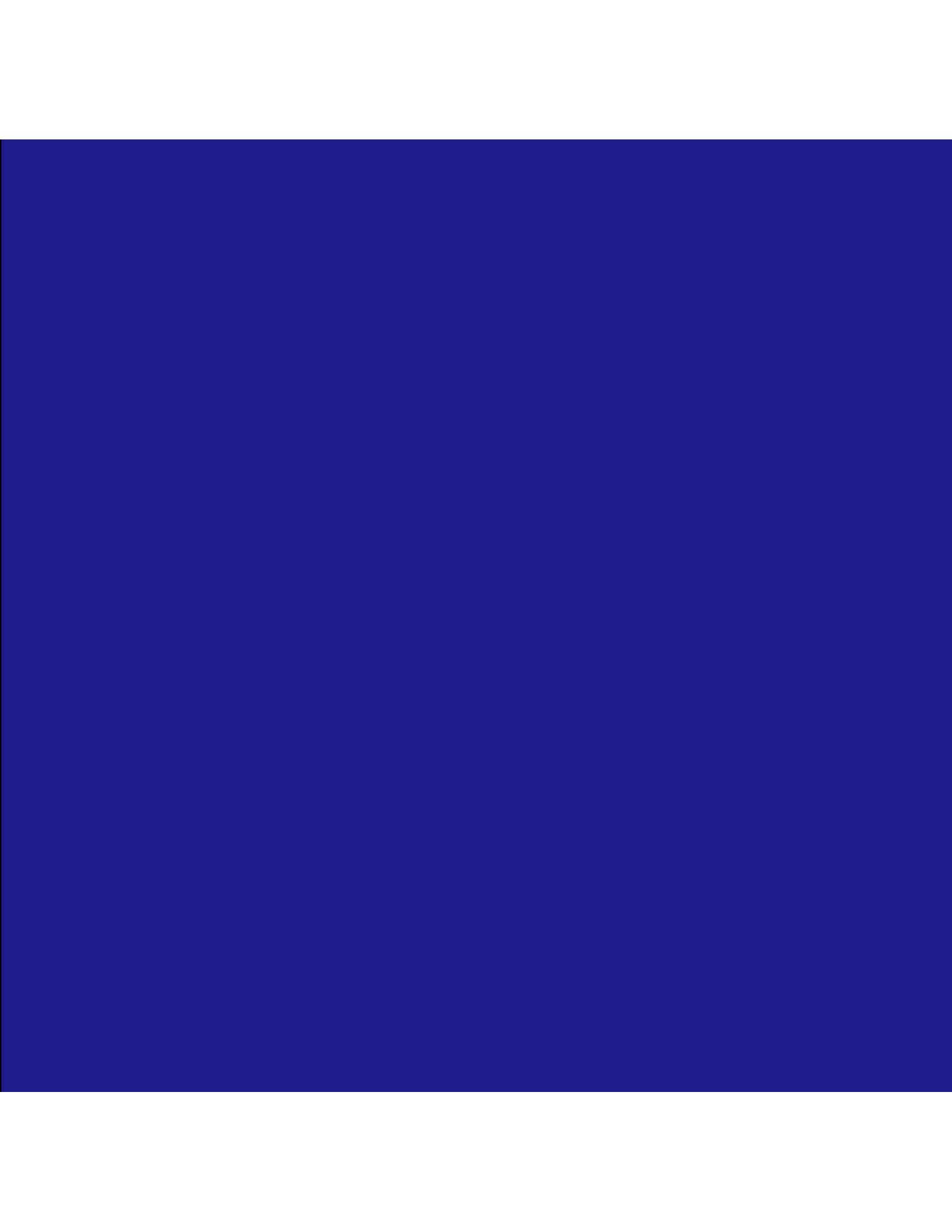
Voices of Detroit Initiative

West Virginia Community Voices Partnership



W.K. Kellogg Foundation

The W.K. Kellogg Foundation launched Community Voices in August 1998 to help ensure the survival of safety-net health providers and to strengthen community support services. Building up from the community level, the project is giving the underserved a voice to help make health care access and quality part of the national debate.





**W.K. KELLOGG
FOUNDATION**

One Michigan
Avenue East
Battle Creek, MI
49017-4058
USA

Voice and TDD: 616-968-1611

Facsimile: 616-968-0413

Telex: 4953028

Internet: <http://www.wkkf.org>